Improving Palliative Care in Long Term Care Homes Using Participatory Action Research

Clinical Frailty Network Conference
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As the population continues to age, more people will die in long term care (LTC) homes. These people represent one of society’s most frail and marginalized populations who often struggle with managing multiple chronic conditions and social isolation. Palliative care is complicated for residents who suffer with dementia due to the gradual loss of their cognitive abilities. 

- decision-making related to care needs often rests with family members or health care professionals but **decision making often occurs too late and in crisis mode**
Need for a Palliative Approach in LTC

- Palliative and end-of-life care is poorly managed
  - Poor symptom management
  - Lack of discussions about advance care planning or end of life issues
  - Inappropriate hospitalizations
  - Too many resident deaths in hospital

- Most LTC homes do not have a palliative program
5 Year Project (2009-2014)

• Goal of the Community University Research Alliance funded by the Social Sciences and Humanities Research Council (SSHRC) entitled *Improving the Quality of Life of People Dying in Long Term Care Homes* was to improve quality of life for people who are dying in LTC homes through developing palliative care programs using a process of community capacity development.

• Developed toolkit for other LTC homes to access: www.palliativealliance.ca

• SPA-LTC builds on this work by implementing and evaluating some of these tools.
Research Approach

Participatory Action Research (PAR) – aims to pursue action and sustainable change

- Evidence from previous work to support use of PAR
  - Staff empowerment, development of care practices in collaboration with partners, collaborative learning and teamwork
- SPA-LTC program components consistent with PAR (e.g., Champion Teams, Advisory Board, engaging local resources – Palliative Community Consultants to build capacity in LTC)
- Program Components Shift with feedback and evaluation
Study Objectives

1. Conduct an environmental readiness assessment of the LTC intervention sites to identify factors that may promote or hinder successful implementation of the palliative care program and to address the barriers to its implementation

2. Implement the palliative care program within a participatory action approach

3. Evaluate outcomes for residents (i.e., comfort), family (i.e., satisfaction with care), staff (i.e., knowledge, self-efficacy in palliative care), and organizations (i.e., gaps in palliative care, hospital transfers and deaths)

4. Explore how and why different factors (e.g., resident, family member, staff, components of the program, organizational features), support or impede implementation of the palliative care program and impact study outcomes
Research Design

Mixed methods to address all research questions
- Focus group data
- Surveys
- Chart data

Multiple Case Study Design
- 4 LTC sites as ‘cases’ that represent a mix of contexts found in LTC homes (e.g., profit vs not-for-profit, rural vs urban, administrator turnover, facility size)
Strengthening a Palliative Approach in Long Term Care (SPA-LTC) Core Components

- Develop PC Champion Team
  - opinion leaders
  - meet monthly

- Hold Comfort Care Rounds
  - meet bimonthly
  - PC consultant to attend
  - education and reflection

- Care Conferences
  - occurs: 6 weeks post admission
  - goals of care discussed with family/resident and IP team

- Implement PPS
  - weekly if <30%
  - monthly if > 30%

- Bereavement Follow-up
  - occurs 1 month post-death
  - LTC staff calls family to provide support and referral if needed

- EOL Family Care Conferences
  - occurs if PPS<40%
  - family completes questionnaire before FCC
  - family meets with IP team

Advisory Board: Partners & Decision Makers

Community Palliative Care Consultants

Research Team
Family Care Conference

End of Life Family Care Conferences

https://www.youtube.com/watch?v=l-wvY9Mkqk8
Family Care Conference

Triggered by PPS score (<40%)

A meeting held with staff, family and residents (if possible) to discuss end-of-life care

Designed to help family and residents to:

- Clarify their goals and preferences for care
- Consider the site of care options (LTC, home, or hospital)
- Share information with staff and develop a partnership with staff
- Obtain informed consent about goals of care
Illness Trajectory Pamphlets

• To support pro-active discussions between residents, families and staff in advance of need
  • Palliative care is not only for the actively dying

• To offer information and resources that can be accessed and a resident’s/family members’ pace
  • Illness specific

• To help staff initiative pro-active discussions
  • They are often uncomfortable with initiating these conversations
Advanced Frailty

Tips for Family and Friends

- Before a care decision is made:
  - Consider your relative or friend’s end of life values and preferences
  - Stay informed and ask questions
  - Encourage your relative or friend to be as independent and participate in as many decisions as he or she is able

- With a health care provider, explore and discuss options:
  - To prevent or reduce injury from falling
  - To prevent or reduce confusion (e.g., discontinue unnecessary medications)
  - To manage symptoms from multiple chronic conditions
  - For diet (e.g., supplements to deal with swallowing problems or weight loss)
  - For dealing with fatigue (e.g., promote physical activity)

Your health is important too. If you are feeling overwhelmed, seek support from the Family Councils of Ontario:

- www.fco.org
- Phone: (416) 487-4355
- Toll-Free: 1-888-283-8806

What Should I Ask About?

- What are my or my relative or friend’s biggest fears about his/her health?
- How can I help maintain my or my relative or friend’s quality of life?
- What should I expect when I am or my relative or friend is dying?

Online Resources

1. John Hopkins Medicine: tips for staying healthy, helpful definitions
   http://www.hopkinsmedicine.org/health/healthy-agency/health-body/stay-healthy-ways-to-beat-the-frailty-risk

2. City of Toronto: family LTC resources
   Go to http://www1.toronto.ca/
   Search “Long-term care family education”. Select the first link.
   Topics include: assistive devices, decision-making, finances, etc.

3. Main Line Gastroenterology Associates (MLGA):
   http://mainlineag.com/patient-education/how-are-you-done/MLGAPHASES

A Resource for Residents, Family and Friends

The Palliative Approach for Advanced Frailty in Long Term Care

Version 2

What is a Palliative Approach?

This pamphlet was made to help persons with Advanced Frailty and their families know what to expect at the end of life so they can plan ahead. Talking about preferences early on is an important first step to a Palliative Approach to Care.

A Palliative Approach:

- Is for residents in long term care (LTC) with conditions that have no cure
- Shifts focus from prolonging life to maintaining quality of life
- Is an active approach that can start at any stage of chronic illness
- Is part of usual care
- Does not require a referral

What is Frailty?

Frailty is a chronic progressive life-limiting illness. This means that symptoms worsen over time and may affect how long one lives. Frailty is:

- An age-related decline in health
- Linked to cognitive problems and having multiple chronic conditions (e.g., dementia, heart disease, cancer)

Final residents:

- Are at higher risk for falls, hospital admission, disability, and death
- Have problems with multiple body systems

How does Frailty progress?

It is difficult to predict how long frail persons may live, so it is good to hope for the best and plan for the worst.

- Treatment of all conditions
- Pain and symptom management
- Social and spiritual support

For more information, please visit:

www.toronto.ca
www.advancecareplanning.ca

Physical Function

Disease Progression

Acute event (e.g., hospitalization)

Physical Function

- Muscle mass, and strength (weakness)
- Energy (fatigue)
- Walking speed or mobility
- Activity levels (lies in bed or sits in a chair for most of the day)
- Ability to do daily activities (e.g., eating, toileting, bathing, walking)
- Appetite (weight loss)
- Cognitive function

The end stage of frailty is called “failure to thrive”. It may be related to one or more diseases.
Advanced Dementia

Tips for Family and Friends

Before a care decision is made:
- Consider your relative or friend's end of life values and preferences
- Stay informed and ask questions
- Encourage your relative or friend to be as independent and participate in as many decisions as he or she is able

With a health care provider, explore and discuss options:
- To learn about how your relative or friend expresses feelings through his/her behaviour
- For communication (e.g. play music, show pictures, animals, and tell comforting stories)
- For eating if your relative or friend can no longer swallow food
- To maintain physical/social activities

Your health is important too. If you are feeling overwhelmed, seek support from the Family Councils of Ontario

www.fcno.ca
Phone: (416) 487-4355
Toll Free: 1-888-283-8806

What Should I Ask About?

- What are my or my relative or friend’s biggest fears about my/his/her health?
- How can I help maintain my or my relative or friend’s quality of life?
- How long can someone be in the late stages of dementia?
- What should I expect when I am no longer able to care for my relative or friend?

Online Resources

1) Alzheimer Society of Canada:
booklets-and-publications
2) Alzheimer’s Disease Education and Assistance Program (ADEAP) at the Alzheimer’s Association of Canada:
http://www.alz.org/alzheimer_s_disease_publications.asp
3) Comfort Care at the End of Life:

The Palliative Approach for Advanced Dementia in Long Term Care

Version 4

A Resource for Residents, Family and Friends

What is a Palliative Approach?

This pamphlet was made to help persons with Dementia and their families know what to expect at the end of life so they can plan ahead. Talking about preferences early on is an important first step to a Palliative Approach to Care.

A Palliative Approach:
- It is for residents in long term care (LTC) with conditions that have no cure
- Shifts focus from prolonging life to maintaining quality of life
- Is an active approach that can start at any stage chronic illness
- Is part of usual care
- Does not require a referral

How does Dementia progress?

It is difficult to predict how long someone with dementia may live, so it is good to hope for the best and plan for the worst.

Dementia is a chronic progressive life-limiting illness. This means that symptoms worsen over time and may affect how long one lives. Dementia:
- Affects a person’s thinking, mood, language, and behaviour
- Is a group of illnesses (e.g., Alzheimer’s, Vascular, Fronto-temporal, Lewy Bodies, and Parkinson’s dementia)

Residents with dementia:
- Will have bad days (more confusion) and good days (less confusion)
- Can live for years

Living with Dementia

The progression of dementia cannot be reversed and there is no cure. Being well-informed will help you to make care decisions.

Late or Advanced Stage Signs:
- Severe memory loss (e.g. names, events)
- Loss of concept of time and space
- Difficulty with speech/language (aphasia)
- Loss of ability to use toilet, bathe and walk without help
- Difficulty swallowing (pneumonia risk)
- Reduced interest in activities

End of Life Stage Signs:
- Change in circulation (e.g. cold hands/feet, skin breakdown)
- Gastrointestinal failure
- Pain, shortness of breath or agitation.
Advanced Heart Failure

Tips for Family and Friends
- Before a care decision is made:
  - Consider your relative or friend's end of life values and preferences
  - Stay informed and ask questions
  - Encourage your relative or friend to be as independent and participate in as many decisions as he or she is able

With a health care provider, explore and discuss options:
- For drugs to help with shortness of breath and fluid retention
- Before you give your relative or friend any over the counter drugs (e.g. Advil) or natural health products
- For diet (e.g. low salt intake or dealing with low appetite)
- For dealing with fatigue (e.g. promote physical activity)

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www.fcoc.org
Phone: (416) 487-4355
Toll-Free: 1-888-283-8806

What Should I Ask About?
- What are my or my relative or friend's biggest fears about his/her health?
- How can I help maintain my or my relative or friend's quality of life?
- What symptoms do I, my relative or my friend have that are related to HF?
- What are the options when I am or my relative or friend is no longer responding to the HF medication?
- What should I expect when I am or my relative or friend is dying?

Online Resources
1) Heart Failure Matters: interactive website that explains HF
   www.heartfailuermatters.org
2) BC Heart Failure Network: documents for HF self-care
   www.heartfailure.ca/for-patients-and-families/co-management-resources
3) American Heart Failure Society: 10 modules (medications, end of life)
   www.heartfailure.ca/for-patients-and-families/co-management-resources

The Palliative Approach for Advanced Heart Failure in Long Term Care

What is a Palliative Approach?
This pamphlet was made to help persons with Heart Failure (HF) and their families know what to expect at the end of life so they can plan ahead. Talking about preferences early on is an important first step to a Palliative Approach to Care.

A Palliative Approach:
- Is for residents in long-term care (LTC) with conditions that have no cure
- Shifts focus from prolonging life to maintaining quality of life
- Is an active approach that can start at any stage of chronic illness
- Is part of usual care
- Does not require a referral

A Palliative Approach includes:
- Treatment of common conditions
- Pain and symptom management
- Social and spiritual support

For more information, please visit:
www.carepartners.ca
www.ontariohealthinformation.ca
www.advancedcareplanning.ca

What is HF?
HF is a chronic progressive life-limiting illness. This means that symptoms worsen over time and may affect how long one lives. HF:
- Occurs when the heart is not pumping as strongly as it should
- Causes fluid to back up from blood vessels into the lungs and legs

Residents with HF:
- Will have bad days (more symptoms) and good days (less symptoms)
- Can live for months or years

How does HF progress?
It is difficult to predict how long someone with HF may live, so it is good to hope for the best and plan for the worst.

Disease Progression
- Acute event
- Heart Function
- Disease Progression

Living with HF

The progression of HF cannot be reversed and there is no cure. Being well-informed will help you to make care decisions if you are able.

Talk to your or your relative or friend's health care provider if you notice:
- More weakness or tiredness (fatigue)
- More shortness of breath with little activity or at rest
- Weight gain (fluid retention) or weight loss (muscle loss or loss of appetite)
- More swelling in lower legs (edema) or in abdomen (ascites)
- Coughing (with or without sputum) that may worsen when lying down
- Rapid or irregular heart rate at rest
- More problems with cognitive function
Advanced Kidney Disease

Tips for Family and Friends

Before a care decision is made:
- Consider your relative or friend’s end of life values and preferences
- Stay informed and ask questions
- Encourage your relative or friend to be as independent and participate in as many decisions as he or she is able

With a health care provider, explore and discuss options:
- For drugs (e.g. allergy pills) or creams (e.g. calamine lotion or Unisom) to help with itching
- For clothing to help reduce itching (e.g. cotton)
- For diet (e.g. low protein and salt, ways to deal with low appetite/desire)
- For dealing with fatigue (e.g. promote physical activity)

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www.fco.org
Phone: (416) 487-4355
Toll-Free: 1-888-283-8806

What Should I Ask About?

- What are my or my relative or friend’s biggest fears about his/her health?
- How can I help maintain my or my relative or friend’s quality of life?
- What symptoms do I, my relative or my friend have that are related to AKD?
- What are the options when I am or my relative or friend’s kidney function is too low to respond to medications?
- What should I expect when I am or my relative or friend is dying?

Online Resources

1) National Kidney Foundation (US):
   https://www.kidney.org/store/storeTopicBrochures
2) Ontario Renal Network: Dialysis and other Ontario CKD services.
   http://www.renwnetwork.on.ca/info_for_patients/#/viAsaC6TvVo
3) Renal Resource Centre (Australia):
   http://www.renallresource.com/pdf/lectureGCKD.pdf
4) Kidney Foundation of Canada:
   http://www.kidney.ca/brochures

The Palliative Approach for Advanced Kidney Disease in Long Term Care

A Resource for Residents, Family and Friends

What is a Palliative Approach?

This pamphlet was made to help persons with Advanced Kidney Disease (AKD) (also called CKD) and their families know what to expect at the end of life so they can plan ahead. Talking about preferences early on is an important first step to a Palliative Approach to Care.

A Palliative Approach:
- Is for residents in long term care (LTC) with conditions that have no cure
- Shifts focus from prolonging life to maintaining quality of life
- Is an active approach that can start at any stage of chronic illness
- Is part of usual care
- Does not require a referral

What is AKD?

AKD is a chronic progressive life-limiting illness. This means that symptoms worsen over time and may affect how long one can live. AKD:
- Is also called end-stage renal failure
- Is mostly caused by hypertension (high blood pressure) or diabetes
- Occurs when the kidneys are no longer able to filter blood (kidney function is less than 15%)
- Causes wastes to build up in the body

Residents with AKD can live without symptoms for months or years.

How does AKD progress?

It is difficult to predict how long someone with AKD may live, so it is good to hope for the best and plan for the worst.

For more information, please visit:
- www.virtualhospice.ca
- www.advancedcareplanning.ca

Living with AKD

The progression of AKD cannot be reversed and there is no cure. Being well-informed will help you to make care decisions if you are able.

Talk to your or your relative or friend’s health care provider if you notice:
- Dry and itchy skin
- Confusion and sleep problems
- Lack of energy and tiredness (fatigue)
- Metallic taste in mouth
- Low appetite or weight loss
- Nausea and vomiting
- Shortness of breath
- Swelling of ankles (edema)
- Pale skin or coldness (low body temperature)
Advanced Lung Disease

Tips for Family and Friends

Before a care decision is made:
- Consider your relative or friend's end of life values and preferences
- Stay informed and ask questions
- Encourage your relative or friend to be as independent and participate in as many decisions as he or she is able

With a health care provider, explore and discuss options:
- To help with shortness of breath and coughing (e.g., opioids, oxygen therapy, bronchodilator techniques)
- To prevent infections (e.g., hand washing, flu and pneumonia shots, avoid touching face)
- For diet (e.g., dealing with loss of appetite)
- For dealing with fatigue (e.g., promote physical activity)

Your health is important too. If you are feeling overwhelmed, seek support from the Family Council of Ontario.

www.fco.org
Phone: (416) 487-4355
Toll-Free: 1-888-263-8006

What Should I Ask About?

- What are my or my relative or friend's biggest fears about his/her health?
- How can I help maintain my or my relative or friend's quality of life?
- What symptoms do I, my relative or my friend have that are related to ALD?
- What are the options if I develop or my relative or friend develops heart failure as a result of ALD?
- What should I expect when I am or my relative or friend is dying?

A Resource for Residents, Family and Friends

The Palliative Approach for Advanced Lung Disease in Long Term Care

Version 2

Online Resources

1) Lung Association:
- Symptoms and signs of flare-ups
- Breathlessness and oxygen therapy
- Fatigue and exercise
2) COPD Foundation: symptoms, medications, oxygen, and webinars
www.copdfoundation.org

What is a Palliative Approach?

A Palliative Approach includes:
- Treatment of curable conditions
- Pain and symptom management
- Social and spiritual support

For more information, please visit:
www.virtualhospice.ca
www.advancecareplanning.ca

What is ALD?

ALD is a chronic progressive life-limiting illness. This means that symptoms worsen over time and may affect how long one lives. ALD:
- Occurs when damaged lungs are not exchanging oxygen and carbon dioxide as well as they should
- Is a group of chronic lung illnesses (e.g., emphysema, chronic bronchitis, bronchiectasis, and asthma)

Residents with ALD:
- Will have bad days (more symptoms) and good days (less symptoms)
- Can live for months or years

How does ALD progress?

It is difficult to predict how long someone with ALD may live, so it is good to hope for the best and plan for the worst.

Acute event (flare-up)

Disease Progression

Living with ALD

The progression of ALD cannot be reversed and there is no cure. Being well-informed will help you to make care decisions if you are able.

Talk to your or your relative or friend's health care providers if you notice:
- More shortness of breath with little activity or at rest
- More weakness or tiredness (fatigue)
- Cough and wheezes with more sputum
- Decreased activity level (stays in bed or chair)
- Low appetite and weight loss
- Swelling in feet and ankles (edema)
- More hospital visits or respiratory tract infections
- More problems with cognitive function
Key Findings
**Total (N=551)**

**Staff completed PPS on all residents**

**PPS >50%**
- N=428 (78%)

**PPS 30-40%**
- N=110 (20%)

**PPS <30%**
- N=5 (1%)

**Residents enrolled in study**
- N=40

**Family Care Conferences held**
- N=24

**Residents who died**
- N=11

**Time from FCC to death:**
- Range: 2 weeks – 6 months
- n=1
- n=7

**Time from FCC to death:**
- Range: 2 days – 2 weeks
- n=2
- n=1

n= 8 residents missing PPS scores

n= 2 residents died before being recruited into the study
## Resident Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>FCC (n=24)</th>
<th>No FCC (n=16)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Male</td>
<td>9 (37.5)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>15 (62.5)</td>
<td></td>
</tr>
<tr>
<td>Age at enrollment (years)</td>
<td>86 (9)</td>
<td></td>
</tr>
<tr>
<td>Length of Stay in LTC (years)</td>
<td>6.7 (3)</td>
<td></td>
</tr>
<tr>
<td>Dementia</td>
<td>22 (92%)</td>
<td></td>
</tr>
<tr>
<td>Charlson Comorbidity Index</td>
<td>7.75 (2)</td>
<td></td>
</tr>
<tr>
<td>Duration from FCC to death (weeks)</td>
<td>7.11 (9.9) weeks</td>
<td>Range: 2 days-6mos</td>
</tr>
<tr>
<td>Died in LTC</td>
<td>9 (100%)</td>
<td></td>
</tr>
</tbody>
</table>

FCC = Family Care Conference
Staff Participation in Family Care Conferences

<table>
<thead>
<tr>
<th>Discipline / Role</th>
<th>Family Care Conference (n=24)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing (RN/RPN)</td>
<td>21 (88%)</td>
</tr>
<tr>
<td>Social Work</td>
<td>13 (54%)</td>
</tr>
<tr>
<td>Recreational Therapy</td>
<td>11 (46%)</td>
</tr>
<tr>
<td>Director/Assistant of Care</td>
<td>9 (38%)</td>
</tr>
<tr>
<td>Dietary</td>
<td>9 (38%)</td>
</tr>
<tr>
<td>Physician</td>
<td>8 (33%)</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>3 (13%)</td>
</tr>
<tr>
<td>Personal Support Workers</td>
<td>3 (13%)</td>
</tr>
</tbody>
</table>

> 4 disciplines attended on average
## Family Participation in Family Care Conferences

<table>
<thead>
<tr>
<th>Relationship to Resident</th>
<th>Family Members Attending FCCs (n=24)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Husband</td>
<td>1 (4%)</td>
</tr>
<tr>
<td>Wife</td>
<td>3 (13%)</td>
</tr>
<tr>
<td>Daughter/in-law</td>
<td>13 (54%)</td>
</tr>
<tr>
<td>Son/in-law</td>
<td>11 (46%)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (8%)</td>
</tr>
<tr>
<td>Variable</td>
<td>Pre N=551</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>Deaths</td>
<td>26%</td>
</tr>
<tr>
<td>• In hospital</td>
<td>28%</td>
</tr>
<tr>
<td>• At LTC home</td>
<td>72%</td>
</tr>
<tr>
<td>ER Visits in the last year of life</td>
<td>65%</td>
</tr>
<tr>
<td>• Last month of life</td>
<td>46%</td>
</tr>
<tr>
<td>• Last week of life</td>
<td>27%</td>
</tr>
<tr>
<td>• Average # of ER Visits/resident</td>
<td>1.2</td>
</tr>
<tr>
<td>→ Planned/Appropriate visits</td>
<td>83%</td>
</tr>
<tr>
<td>→ Unplanned/Inappropriate visits</td>
<td>17%</td>
</tr>
<tr>
<td>• Became hospital admissions</td>
<td>89%</td>
</tr>
</tbody>
</table>
Thank You!

Sharon Kaasalainen – kaasal@mcmaster.ca